CHAPTER 12:

Permanency Planning

One of the 11 sites participating in the HIV/AIDS Mental Health Services Demonstration Program devoted its treatment approach to permanency planning. This chapter reflects the lessons learned from the Kinship Connection Program in Elizabeth, New Jersey—as well as the collective experience of the other 10 projects.

Permanency planning is the process by which custodial parents living with HIV develop a viable plan for the future care of their minor children in the event of their own death. For the purposes of this chapter, the term "caregiver" refers to the person selected by the parent to take responsibility for the future care of the children. Permanency planning can be done by any individual who has legal custody of minor children—whether he/she is the biological parent, an adoptive parent, a grandparent, an aunt, an uncle, or another individual.

Planning for the future care of the child is a very emotional and difficult task for the parent. Acknowledgement of the need for permanency planning does not necessarily mean that the custodial parent is ready to take the necessary steps to start working on permanency plan. Engaging the client, building trust, and assessing the client's readiness is crucial to completing the permanency planning process. Likewise, it is in the best interests of the parents and the children to face the decision about who will be the future caregiver of the children after the parent dies. It is very important that this decision be made while the parent is still capable of making an informed and competent decision.

Unquestionably, permanency planning is difficult. It involves thinking about the illness and one's potential death. Many parents facing death intend to leave their children with relatives in some kind of informal adoption, not realizing the importance of planning, discussing it, and making a "legal plan" ahead of time. Parents can make the most appropriate decision for their children if they are well-informed of all available legal options. Many parents with HIV fear the many legal mazes that they must go through to secure a safe and viable family for their children. They also may fear Child Protective Services, the possibility of losing their parental rights, or having their children removed from their home before it is necessary.

Permanency planning also is difficult because some clients may feel that completing a permanency plan and "taking care of business" equals giving up—not knowing that developing a permanency plan may also bring peace of mind.

Facts About HIV, Women, and Their Children

Women—especially those in their child-bearing or child-rearing years—continue to become the fastest growing segment of the population to be infected with HIV or diagnosed with AIDS. Consequently, there is a corresponding increase in the number of children who are directly affected by HIV. For example, it is estimated that, by 2000, between 72,000 and 125,000 children and teenagers in the U.S. will have lost their mothers to HIV. An additional 60,000 young adults (18 and older) also will have lost their mothers (Levine & Stein, 1994).

Charlotte's Story

Charlotte was referred to treatment after she was diagnosed with advanced HIV infection. Charlotte had three children—two boys ages 6 and 12, and a girl age 14. Charlotte lived alone with her children. She also had a history of drug use.

After becoming engaged in the permanency planning process, Charlotte identified her mother, as the potential guardian for her children. But she soon changed her mind and identified her sister Karen as the preferred future caregiver, with her other sister as a back-up potential guardian.

Steps to complete the permanency planning process were taken. Case workers met with both of Charlotte's sisters to determine if each sister would be able to carry out the plan. Regular meetings between both of Charlotte's sisters and her children were held. An attorney made the plan legal.

Then Charlotte's health rapidly began to deteriorate. Because of HIV-associated dementia, Charlotte was unable to care for her children. At one point, Charlotte called her lawyer and ordered that her will and custody plan be changed so that a hospital employee would get custody of her children. Charlotte's sisters went to court, and the court gave custody of Charlotte's children to Karen, based on Charlotte's previous permanency plan. Charlotte went into hospice care. She died soon after.

Karen had a difficult time with her niece and nephews. They were not accustomed to having rules. They exhibited behavioral problems—both at home and at school—and they consistently received D's and F's in school. Program staff, however, continued to provide mental health and case management services, including bereavement counseling and a range of other services.

Today, Charlotte's children are earning A's and B's in school. Their behavior has improved, and they have adjusted to their new home.

The 12 Steps of Permanency Planning

1. Assist the parent in feeling comfortable with the idea.
2. Determine whether or not the parent has discussed his/her illness with the potential caregiver.
3. Talk to potential future caregiver(s).
4. Identify and address potential legal and non-legal barriers to the custody plan.
5. Find out who lives with the future caregiver or who visits frequently so that the child's physical, emotional, and sexual safety is protected.
6. Assess the future caregiver's readiness and availability to care for the children (e.g., health status, financial status, and housing situation).
7. Get the children involved at the appropriate time.
8. Try to keep siblings together. If this is not possible, help future caregivers understand and plan the need for frequent contact between siblings in the future.
9. Assist in planning and easing transitions into new schools, when necessary.
10. Determine when it is an appropriate time for the child and the future caregiver to start spending more time together.
11. Obtain legal approval of the custody plan.
12. Provide ongoing counseling and case management, as needed.

WHY PERMANENCY PLANNING IS IMPORTANT

Permanency planning is important for many reasons:

- If there is no custody plan, individuals other than the custodial parent will have to make several important decisions when the parent becomes too ill or after the parent's death. These decisions will be necessary at a time when the children and the possible caregiver will be grieving.
- The informal caregiver, even if he/she is a close relative, has no legal authority to make decisions on the child's behalf, such as enrolling the child in school, obtaining health insurance coverage or affordable health care, or securing other services the child may need.
- Child Protective Services may be required to intervene by placing children in foster homes, which may result in separating siblings.
- Final decisions may be made by the court, without hearing the parent's wishes, and the court's decision may not be what the parent wanted.

parents, children, future caregivers, attorneys, case managers, family therapists, other family members

THE PARTIES INVOLVED IN PERMANENCY PLANNING

Depending on the situation, permanency planning can involve several individuals who share an interest in carrying out the parent's wishes and protecting the children and their future. For example:

- The parent explains his/her wishes and makes decisions about the future care of the children.
- The children identify their preferences and dislikes, provide reactions to different options, and prepare to adjust to new living arrangements.
- The future caregiver expresses his/her availability, willingness, and readiness to assume new responsibilities for the children. At the same time, program staff can assess the caregiver's ability to care for the children and make arrangements for additional services and support systems.
- The attorney advises the client on his/her legal options, remaining sensitive and responsive to the client's unique legal needs.
- The case manager coordinates the full range of services that are needed to support the parent, the children, and the caregiver; ensures continuity of care; and advocates on behalf of the client and the reconfigured family.
- The family therapist assists the client, the child, and the future caregiver in dealing with the parent's illness—including issues associated with denial, stigma, isolation, disclosure to the caregiver and/or child, and coping with HIV and its effect on the family. The therapist also facilitates the permanency planning process from beginning to end by maintaining contact with the child and the future caregiver after the parent's death to ensure continuity of therapy and permanency of the plan.
- Other family members and friends can be active participants in developing and implementing the permanency plan and in supporting the identified caregiver.

BENEFITS OF INVOLVING FAMILIES

The benefits of involving families in the permanency planning process include the following:

- It is empowering and can help the custodial parents retain a sense of control.
- Permanency planning minimizes disruptions in the child's life. For example, the child will not be bounced from one family member to another and will have an opportunity to gradually spend time with the potential caregiver as a way to ease transition into the caregiver's family. The ultimate goal is to meet the child's need for continuity, familiarity, and stability.
- It can ease the transition for the parent, the child, and the caregiver by addressing needs, fears, and concerns prior to and during the transition into the caregiver's family.
- Decisions can be made that may help keep all siblings together. If that is not possible, arrangements can be made for siblings to get together during special occasions, such as birthdays, anniversaries, holidays, etc.
- Parent, child, and caregiver family needs can be identified so that all needed support services are put in place to ensure the viability of the plan.
- The parent, the children, and the caregiver are afforded an opportunity to discuss concerns and/or potential problems with the potential permanency plan.
- Involving the concerned parties in this process helps to minimize the potential for future legal custody battles once the permanency plan is implemented.
- When an infected parent is using alcohol or other drugs and refuses to discuss permanency planning, program staff may be able to work with the individual who supervises the client's children, a family member, or someone else close to the client who is interested in protecting the children in the future.

Whenever possible, children should be active participants

WHEN TO GET FAMILIES INVOLVED

The sooner custodial parents begin to confront permanency planning the better. Many parents agree to work on permanency planning issues, but they may not be ready to do it when it is brought up for the first time. Permanency plans take time to develop and the amount of legal paperwork may be daunting, especially in cases where there is the potential for custody battles. In spite of these challenges, clients should be encouraged to begin permanency planning as soon as they are willing and able to make these decisions.

While there is no easy time to bring up the need for permanency planning, some times may be better than others. For example, if a parent is hospitalized and has not yet developed a permanency plan, he/she may be more prepared to discuss the possibility when hospitalized. Clinicians can use this opportunity to discuss the options and resources available to the client.

HIV-affected children also require a careful approach to engagement. Program staff can encourage parents to allow their children to be engaged at an appropriate point in the permanency planning process. Whenever possible, children should be active participants in permanency planning so they can begin to identify preferences. In fact, if a custody plan is reviewed by the court, many judges will ask older children to indicate their preferences for a potential caregiver.

Future caregivers also play an important role in permanency planning. Identifying the future caregiver early in the process ensures that he/she is aware of and in agreement with the plan itself. This provides an opportunity to assess the caregiver's ability to carry out the permanency plan and to determine what services may be necessary to help him/her care for the children, such as support systems, appropriate housing, financial resources, insurance coverage, and other potential services. This also provides an opportunity for the future caregiver to spend time with the children (e.g., staying overnight), which can help ease the transition for all parties involved.

LEGAL OPTIONS AVAILABLE TO PARENTS

It is important to educate and empower parents regarding the different permanency planning and guardianship options available. The following brief descriptions of current legal options available to families are provided for educational purposes only. Before any actions are taken, one should consult an attorney in the state of residence.

A will is a legal document used to record a person's wishes upon his/her death. It may include a nomination of a caregiver who will serve as the child's future guardian. Drafting a will is relatively simple and allows a parent to retain full legal custody of the children until death. However, a will does not guarantee placement with the parent's chosen guardian. Following the death of the parent, the chosen guardian must petition the court. The court then determines what it believes to be in the best interest of the child. If there is a surviving biological parent, he/she will have to consent to the chosen guardian. A biological parent will most likely be successful in gaining full custody if he/she wishes to seek custody after the parent's death. A will is only a method to indicate a "preference" and is not binding as a final determination.

Adoption is the most permanent form of placement. In an adoption, the parental rights are "terminated" and transferred to the adoptive parent(s). To initiate adoption, an application or petition must be filed with the court. The petition requires a signed document from both parents giving up their rights over the child. A hearing is then scheduled and the judge makes a final determination. The process may take a year or more. Because of its time and permanency, adoption is impractical and not emotionally feasible for some parents with advanced HIV infection.

Guardianship is a less permanent placement than adoption and usually is a more plausible choice for parents. Guardianship involves a process in which a parent's rights are suspended, allowing the designated guardian to serve as the primary caregiver. A petition must be filed in court, and a judge makes a final ruling after a hearing several weeks later. In the interim, a court-appointed social worker will visit and assess the prospective guardian's home. If there is a surviving biological parent, he/she must consent to the placement, legally abandon the child, or waive his/her rights for placement to proceed. Surviving parents who challenge the appointment may succeed, unless demonstrated to be unfit parents. Once guardianship papers are signed, all parental rights are suspended. The new guardian has legal authority and will not have to take any steps following the parent's death. Although this fairly simple process allows the parent to complete the

process of finding a home for the child before his/her death or disability, the parent must give up his/her parental rights and decision-making authority over the child. In some cases, the parent may be required to give up physical custody of the child as well.

Stand-by Guardianship allows a parent to complete a process to designate a secondary individual as a stand-by guardian to be empowered to assume the parental role immediately on the death or adjudication of incapacity of the last surviving natural parent or adoptive parent of the child. Typically, the statute requires the triggering event to be either the parent's physical debilitation, mental incapacity, or death. Stand-by Guardianship allows parents to care for their children and retain parental rights. However, upon parental death or declared incapacity, the legal authority automatically goes to the stand-by guardian. Under Stand-by Guardianship, a parent can make legal arrangements while still in good health, be involved with these arrangements throughout the court process to insure his/her wishes will be carried out, and retain parental rights until death or incapacity. Stand-by Guardianship is not an appropriate option for every parent. When there are two natural parents, both parents have an equal right to custody of a child. Stand-by Guardianship cannot be established if the other parent desires custody and is able to care for the child. Even when the other parent has been absent from the child's life or has abandoned the child, the custodial parent must always attempt to notify the non-custodial parent of the intent to name a stand-by guardian. The custodial parent must show that the other parent has no intent or desire to seek custody or that the other parent did not respond to the notification. Some states also will allow the custodial parent to show evidence that the non-custodial parent is not a suitable custodian for the child.

Joint Guardianship is a permanency planning option available in only a few states. The primary purpose of Joint Guardianship is to allow a parent to complete the guardianship process while still healthy, without relinquishing or suspending all parental rights. This option allows the parent to choose the legal guardian and allows the child to become familiar with the guardian. However, since Joint Guardianship requires a parent to give up some control of the children by sharing decision making responsibility with the chosen guardian, this may not be a perfect solution for some parents. In those cases, Stand-by Guardianship may be more suitable.

permanency planning offers numerous therapeutic opportunities

Foster care/adoption becomes the option of last resort when parents living with HIV do not have family members or friends to take care of their children or when permanency plans are not in place. Once families are involved in the foster care system, options are limited. In most states, regulations give parents 18 months to correct or make needed changes in their life to regain custody of their children. If the children do not return to their biological parents, the next step is to put them up for adoption. Given that most foster care systems already are overburdened, this process may lead children to a series of placements and risk the possibility that siblings may be separated prior to and/or after adoption.

Because of the psychological implications associated with the permanency planning process, there are numerous therapeutic opportunities. The roles of the worker and mental health clinician are important. (See Chapter 4 on Mental Health Services, Chapter 8 on Psychotherapy and Counseling, and Chapter 9 on Counseling Themes and Clinical Considerations.)